

CHAPTER VIII

CSHCN

Overview

The Maternal and Child Health Bureau (MCHB) defines CSHCN as: “children who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, 1998). There is no agreement on an approach for identifying children who are at-risk under this definition, so most discussions of this population focus on children who have a condition and are in need of services. This represents a very broad population of children with a wide range of conditions and need for services.

Idaho CSHCN and their families receive services from a wide variety of agencies and providers. Some of the most important include Medicaid, the Infant Toddler Early Intervention Program, and Special Education services provided through local school districts. In addition to these agencies, the State Title V agency has a mandate to address the needs of CSHCN. The Title V Block Grant includes a provision requiring that 30 percent of the Federal Maternal and Child Health Block Grant be allocated for CSHCN. In Idaho this amounts to just over \$1 million of the Federal allocation. Historically BOCAPS has served a very limited portion of the statewide CSHCN population. Through the Children’s Special Health Program (CSHP), BOCAPS provides diagnostic, treatment, follow-up and case management services for children in eight general diagnostic categories. These categories are Cardiac, Cleft Lip and Palate, Craniofacial, Cystic Fibrosis, Neurological, Orthopedic, Phenylketonuria (PKU) and Plastic/Burn. Until October 2004, care was offered through clinics that brought together multiple providers to provide treatment and through case managers who coordinated treatment and care. Reimbursement was available for care not covered by other sources.

BOCAPs is now in the process of joining other State Title V agencies in transitioning from providing direct services to focusing on enabling services, infrastructure, and systems-building. As the cost of providing direct services was exceeding the available Title V funds, it was felt that many of the services could be provided through other means and paid for by Medicaid and private insurance. As of Fall 2004, Title V funds are no longer used to provide support for the CSHCN clinics, except for PKU and Cystic Fibrosis clinics. BOCAPS has made some initial decisions about what services are going to be provided, but has not fully developed a new strategy for addressing the needs of CSHCN. As of now, decisions have been made to fund direct and case management services for the uninsured portion of the low-income CSHCN population diagnosed within the 8 categories served under CSHP. Families with incomes higher than 185 percent of the Federal Poverty Level will continue to be assessed a co-payment for

CSHP services as they were under the old program. Case management services for this limited number of families are provided through a contract with Saint Luke's Regional Medical Center in Boise. The contract covers services provided by a single care coordinator. Other CSHCN families will be able to receive care coordination services through Medicaid and/or the Infant Toddler Program. This transition in services has been difficult, but it represents an opportunity to better serve a wider range of CSHCN than have traditionally received services through the Title V Program. BOCAPs and other agencies have the potential to develop a stronger system of services for CSHCN and their families. This section examines what is known about the CSHCN population in Idaho and the State's progress on achieving key outcomes for those families.

A. Characteristics of the CSHCN Population

The National Survey of Children with Special Health Care Needs conducted in 2001 provides extensive data for children who fall under the broad definition of CSHCN. The survey was designed to obtain a representative sample of over 700 CSHCN children in each State. Because Idaho is a state with a small population, this represents a very robust sample and is an extremely rich data source.

As noted, the Federal definition of CSHCN that is used is very broad. It includes all children who have a functional limitation caused by a chronic health problem as well as those receiving medication or special services for a chronic health problem. This is a far broader population than that served by the CSHP Program and even goes beyond criteria used by more inclusive programs such as Special Education services. Children defined as CSHCN in the National Survey have a wide range of special needs and the level of severity of their problem varies greatly. The range of severity is shown by the answers to two questions about the nature of the child's condition. The results for these questions are shown in Table VIII-1.

Table VIII-1. Severity of CSHCN Conditions	
Health Insurance Status	Percent
Severity of Child's Condition or Problem	
Mild	28.2
Moderate	47.1
Severe	24.7
How much has child's condition affected child's ability to do things other children his or her age do?	
A great deal	21.7
Some	44.8
A very little	33.5

Source: Maternal and Child Health Bureau [MCHB], 2004

While the level of need for families varies, in order for these children to reach their maximum potential and for their families to best meet their needs, a support system needs to be in place. One way of gauging the different needs of such families is to examine what led the children to be classified as CSHCN. Children who are classified as CSHCN because they take medication differ in needs from those who are accessing services such as speech or occupational therapy, and from those who have developmental limitations that restrict their ability to engage in activities typical of other children their age. The percent of children in the different categories in Idaho is shown in Table VIII-2.

Table VIII-2. Reason Child is Classified as a CSHCN	
	Percentage
Receives Medication Only	28.3
Receives Special Therapy Only	20.8
Receives Both Medication and Special Therapy	23.4
Child has a Functional Limitation	27.5
Source: MCHB, 2004 Note: Children with functional limitations may or may not be receiving special therapy, medication, or both.	

In the National Survey of CSHCN there is a great deal of information available on the characteristics of CSHCN and their families. Table VIII-3 displays information on the characteristics of CSHCN in Idaho and the nation as a whole.

Table VIII-3. Who Are the Children With Special Health Care Needs?		
	Idaho	United States
Percentage of children and youth with special health care needs, 0-17 years old	11.5	12.8
Percentage of households with one or more CSHCN	18.6	20.0
Prevalence of special health care needs by age		
Children 0-5 years of age	6.0	7.8
Children 6-11 years of age	12.6	14.6
Children 12-17 years of age	15.7	15.8
Prevalence of special health care needs by sex		
Female	9.7	10.5
Male	13.3	15.0

Table VIII-3. Who Are the Children With Special Health Care Needs?		
	Idaho	United States
Prevalence by Race/Ethnicity		
Hispanic	5.8	8.5
White (non-Hispanic)	12.3	14.2
Black (non-Hispanic)	8.3	13.0
Prevalence by Poverty Level		
0-99 Percent of the Federal Poverty Level (FPL)	14.3	13.6
100-199 Percent of FPL	12.0	13.6
200-399 Percent of FPL	11.4	12.8
400 Percent of FPL	10.8	13.6

Source: MCHB, 2004

There is a somewhat lower percentage of CSHCN in Idaho than in the nation as a whole. This difference is accounted for by lower rates among younger children as the rate among children ages 12-17 is almost equal to the U.S. rate. Across the country, Hispanics are less likely to be identified as CSHCN and the difference between Hispanics and other racial/ethnic groups is even more pronounced in Idaho. Families who meet the Federal definition of poverty in Idaho are slightly more likely to have a CSCHN than those in the rest of the country, while families in all other income groups are less likely to have a CSHCN.

B. Outcomes for CSHCN Examined in the Needs Assessment

There are four outcomes that have been selected for in-depth examination for Idaho's CSHCN population. Achieving these outcomes would go a long way to ensuring that CSHCN have the opportunity to reach their full potential and that their families are provided the support they need to raise their children to the best of their ability. In addition to these outcomes, the Federal Maternal and Child Health Bureau has developed 7 performance measures for CSHCN. These performance measures are included under the four needs assessment outcomes as shown in Table VIII-4.

Table VIII-4. Needs Assessment Outcomes and MCHB Performance Measures	
Needs Assessment Outcomes	MCHB Performance Measures
Children with chronic health problems or disabling conditions use all the primary and preventive services used by typical children.	None
CSHCN use the full range of health-related services needed to maintain their health and well-being and the services to slow, delay, or prevent untoward outcomes resulting from their chronic health conditions or disabilities.	Children will receive coordinated comprehensive care within a medical home.
Families of CSHCN, including their siblings, have access to and use appropriately the full range of health and health-related services required to promote their growth and well-being and manage their conditions or disabilities.	<p>Families of CSHCN will partner in decision-making and will be satisfied with the services they receive.</p> <p>Families of CSCHN will have adequate public and/or private insurance to pay for the services they need.</p> <p>Community-based services systems will be organized so families can use them easily.</p>
CSHCN use out of home childcare, preschool, and ongoing educational services as appropriate to their age, developmental stage, and health condition and/or disability.	<p>Children will be screened early and continuously for special health care needs.</p> <p>Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.</p>

Source: Maternal and Child Health Bureau, 2005.

Outcome 1: Children with chronic health problems or disabling conditions use all the primary and preventive services used by typical children.

Primary and Preventive Care Including Well-child Visits. Like typically developing children, CSHCN have a wide range of health care needs, including a need for basic primary and preventive care. Basic care helps insure early detection of health problems that might be neglected because of a focus on the condition that leads the child to be classified as CSHCN. In the National Survey of CSHCN, respondents were asked whether during the past 12 months their child “needed routine preventive care, such as a physical examination or well-child check-up.” In Idaho, only 64.7 percent of respondents reported that their CSHCN needed such care. This number is rather low and may indicate that parents of CSHCN, like parents of typical children, do not always realize the value of preventive care. This is especially apparent for parents of older children as shown in Table VIII-5 and for parents of Hispanic and non-white children as shown in Table VIII-6. Efforts to encourage the use of such care should recognize a need to target parents of both typical children and CSHCN.

Table VIII-5. Percent of CSHCN Who Were Reported to Need Primary and Preventive Care by Age Group of Child	
Age Group of CSHCN	Percentage
Age 0-5	80.5
Age 6-11	59.9
Age 12-17	63.4
All Children	64.7

Source: MCHB, 2004.

Table VIII-6. Percent of CSHCN Who Were Reported to Need Primary and Preventive Care by Race/ethnicity of Child	
Race/ethnicity of CSHCN	Percentage
White	66.5
Hispanic	52.2
Other	47.4
All Children	64.7

Source: MCHB, 2004.

Among those needing such care, the vast majority of families (95.4 percent) were able to obtain it. While the sample of those not obtaining care is very small, it is important to note that the most common reason given for not obtaining care (66.9 percent of those who did not receive care) was that it cost too much. (MCHB, 2004)

Dental Care. Adequate dental care is an important component of primary and preventive care. Families of CSHCN were more likely to report that they needed dental care, including checkups, than primary and preventive care (82.9 percent to 66.9 percent). As shown in Table VIII-7 the need for dental care increases with age, as very young children do not usually see a dentist. As was the case with primary care, Hispanic families were less likely to report needing a dentist. However, unlike primary care, there was little difference between white families and other race/ethnic groups in need for a dentist. (MCHB, 2004)

Table VIII-7. Percent of CSHCN Who Were Reported to Need Dental Care by Age Group of Child	
Age Group of CSHCN	Percentage
Age 0-5	61.0
Age 6-11	84.6
Age 12-17	88.9
All Children	82.9

Source: MCHB, 2004.

Table VIII-8. Percent of CSHCN Who Reported a Need for Dental Care by Race/ethnicity of Child	
Race/ethnicity of CSHCN	Percentage
White	83.8
Hispanic	68.5
Other	83.1
All Children	82.9

Source: MCHB, 2004.

Most of those CSHCN who say they need dental care were able to obtain it (88.5 percent). Similar to primary care, the most common reason for not obtaining it was that it cost too much (cited by 50.8 percent of those unable to obtain it) (MCHB, 2004). However, these data may underestimate the percent of those CSHCN who are not obtaining needed dental care. There is a clear association between income and type of insurance and whether a family indicates they need dental care as shown in Table VIII-9. This finding may partially reflect different views of the type of care children need in different cultures or among those with different levels of education. However, it is also possible that some families know they will have difficulty accessing care because of cost or because of a lack of providers who accept their insurance, and thus they are less likely to seek care unless the child has a more serious problem.

Table VIII-9. Percentage of Respondents Indicating CSHCN Needed Dental Services in the Past Year	
Income	
0-99 Percent of the Federal Poverty Level (FPL)	74.4
100-199 Percent of FPL	79.6
200-399 Percent of FPL	86.0
400 Percent of FPL	95.2
Insurance Type	
Private Insurance Only	86.8
Public Insurance	77.9
Private and Public Insurance	81.0
Uninsured	72.5

Source: MCHB, 2004.

Eyeglasses and Vision Care. Finally, eyeglasses and vision care is another category of primary and preventive care that children sometimes need. Overall, 36.5 percent of CSHCN needed such care in the 12 months prior to the survey. The vast majority (96.4 percent) in need of this care received it (MCHB, 2004). There was little difference in terms of identifying a need for eyeglasses or other vision care across income groups. However, as shown in Table VIII-10, Hispanics were more likely than other groups to identify a need for eyeglasses or vision care. This difference is relatively small and may be a product of the relatively small size of the Hispanic sample rather than a real difference.

Table VIII-10. Percent of CSHCN Who Were Reported a Need for Eyeglasses or Vision Care	
Race/ethnicity of CSHCN	Percentage
White	36.2
Hispanic	44.1
Other	32.7
All Children	36.5

Source: MCHB, 2004.

Outcome 2: CSHCN use the full range of health-related services needed to maintain their health and well-being and the services to slow, delay, or prevent untoward outcomes resulting from their chronic health conditions or disabilities.

Types of Care Needed and Used. Other than primary care what types of health care do CSHCN need and use? The National Survey of CSHCN asked respondents whether their children needed a wide range of services in the past year and whether they were able to obtain them. The results are shown in Table VIII-11. The service that most families needed was prescription drugs, followed by care from a specialty doctor; medical supplies; physical, occupational or speech therapy; and mental health care or counseling. In all cases most families who said they needed a service were able to obtain them. The services that families found the hardest to obtain were genetic counseling and mental health care.

Table VIII-11. Types of Care Needed and Received by CSHCN		
Type of Care	Percentage Needing Care	Percentage of Those Needing Care Who Received It
Prescription Medicines	86.1	98.0
Care From a Specialty Doctor	53.8	90.5
Medical Supplies	26.3	98.6
Physical, Occupational or Speech Therapy	23.9	91.7
Mental Health Care or Counseling	15.4	75.2
Hearing Aids or Care	7.8	94.8
Genetic Counseling	6.3	76.9
Home Health Care	5.3	97.3

Source: MCHB, 2004.

Table VIII-12 examines some of the reasons CSHCN were unable to obtain different types of care. With the exception of genetic counseling, the most common reason that families of CSHCN were unable to obtain care for each type of care was that it cost too much. The most common reason for not obtaining genetic counseling was that it unavailable in the area.¹ Thus out-of-pocket costs represent barrier to services for quite a few families of CSHCN. Problems with health plans were a factor in preventing families from obtaining medical specialty care, but were a problem for over one-quarter of families unable to obtain physical, occupational or speech therapy and for just over 17 percent of those unable to obtain mental health care or

¹ However, it should be noted that there were too few cases of families who needed, but could not obtain, genetic counseling that the difference between those saying it cost too much and those saying it was unavailable to assess statistical differences.

counseling. This suggests families may need assistance obtaining these types of care either through their insurance or from another source. Finally in regard to mental health care, both key informants and recent Department of Health and Welfare reports and plans mention a shortage of mental health providers for children. This shortage is reflected in the percentage of respondents reporting having difficulties finding providers in the area who are available at convenient times.

Table VIII-12. Reasons Unable to Obtain Needed Care for CSHCN by Type of Care				
Type of Care	Reasons Unable to Obtain Needed Care			
	Cost too much	Problem with health plan	Not available in area or transportation problems	Times service was available was not convenient
Care From a Specialty Doctor	32.1	4.3	14.1	3.1
Physical, Occupational or Speech Therapy	42.5	26.2	4.6	0
Mental Health Care or Counseling	45.1	17.3	15.1	21.4
Genetic Counseling	19.8	0	24.0	0

Source: MCHB, 2004.

While most families who needed specialty care were able to obtain it, the process of accessing that care was not always easy. Almost 18 percent of families reported a problem obtaining a referral as shown in Table VIII-13. This was more likely for families with CSHCN with more severe problems. Part of this difference is likely accounted for by a need for a greater number of referrals for these families.

Table VIII-13. How Often Did a Family Report a Problem Getting a Referral by Severity of Child's Condition	
Severity of CSHCN Condition	Percentage Reporting a Problem Getting a Referral to See a Specialist
All Children	17.9
Mild Severity	7.4
Moderate Severity	15.8
Severe	34.3

Source: MCHB, 2004.

Families who receive Medicaid were more likely to have reported a problem with obtaining a referral as shown in Table VIII-14. A number of things could account for this difference. A

higher percentage of families that use Medicaid report a child with serious conditions and these families may use more specialists and report more problems obtaining specialist care. Also, families with CSHCN in the focus groups indicated that Healthy Connections, the Medicaid managed care program, added an extra step in obtaining specialty care. These parents had to visit their primary care provider (PCP) to obtain a referral even though their child's condition was so serious that the PCP had very limited involvement and understanding of their child's medical situation. Most focus group participants said their PCP agreed to give them referrals without a problem, but they found the extra step of an additional doctor's office visit to be burdensome. It should be noted that this added step is probably not achieving Healthy Connections cost containment goal. If, as parents indicate, PCPs do not feel like they know enough about the care requested to deny it, they also do not know enough to assess whether it is medically necessary. Given the burden it imposes and its limited utility, Medicaid may want to assess whether Healthy Connections is appropriate for children with more severe disabilities.

Table VIII-14. How Often Did a Family Report a Problem Getting a Referral by Type of Insurance	
Type of Insurance	Percentage Reporting a Problem Getting a Referral to See a Specialist
Public Insurance	27.3
Both Public and Private Insurance	26.9
Private Insurance Only	12.8

Source: MCHB, 2004.

Medical Home and Access to Coordinated Care. MCHB has established a goal of having CSHCN receive coordinated comprehensive care through a medical home. Care provided through a medical home should be continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. Under the outcome being discussed in this section, we will explore the extent to which a family receives care from a provider with characteristics of a medical home and the extent to which that care is coordinated. Discussions about the extent that care is family centered are under the next outcome.

One of the features of a medical home is that children receive care from a single provider who knows them. As shown in Table VIII-15, the vast majority of CSHCN have a usual source for care. Most also have someone who is identified as the child's personal doctor or nurse who knows the child best. The Hispanic population is somewhat less likely to be able to identify a usual source of care (74.2 percent) and a personal doctor or nurse who knows their child best (76.7 percent). Over 90 percent of non-Hispanic white families identify a usual source of care, and almost as many (88.2 percent) can identify a personal doctor or nurse for their child. (MCHB, 2004.)

Table VIII-15. Medical Home Indicators: Usual Providers	
CSHCN has a usual source of care	90.2%
CSHCN has a personal doctor or nurse who knows them well	87.6%

Source: MCHB, 2004.

In addition to having a usual source of care it is important that doctors communicate well with other doctors and other programs. As shown in Table VIII-16, doctor's who are excellent or very good at communicating with other doctors are the exception rather than the rule. There are even fewer doctors who are very successful at communicating with other programs. While the numbers for Idaho are not significantly different than in other parts of the country, communication between providers is an important part of a successful medical home. In the Idaho Families of CSHCN Survey, over 85 percent of respondents said it was very important to have a care coordinator available who can coordinate communication between doctors, hospitals, and therapists. This was even higher than the 77 percent who thought care coordination of medical care was very important (Please see Appendix B for more information about this survey). Given the importance of communication and the medical community's shortcomings in this area, efforts are needed to strengthen communication and to develop tools that help providers share information allowing them to better serve children and families.

Table VIII-16. Medical Home Indicators: Communication with Other Providers	
Doctors communicated well with each other (respondents who replied excellent or very good)	48.3%
Doctors communicated well with other programs (respondents who replied excellent or very good)	37.1%

Source: MCHB, 2004.

For many families of CSHCN, access to care coordination is an important component of health care. Care coordination is also a key feature in a medical home. Children may have multiple providers and it is important to have someone who can coordinate services and find additional services when needed. While experts stress the importance of care coordination, it is not clear that parents see things in quite the same way. In the National Survey of CSHCN, only 15.6 percent of Idaho parents of CSHCN reported that their child needed professional care coordination in the past year. This low number may reflect the way respondents defined care coordination or professional care coordinator. It may be that parents have not used care coordination or have had negative experiences so they do not see it as a need. (MCHB, 2004.)

As shown in Table VIII-17 data from the National Survey of CSHCN indicate that care coordination is more frequent for families on public insurance than those on private insurance. This is consistent with findings from the focus groups where families spoke about the lack of care coordination from private insurance plans. Those with private plans generally said they were on their own in terms of arranging care and making connections with providers.

Table VIII-17. How Often Does a Professional Help Coordinate Child's Care by Type of Insurance Among Those Needing Professional Care Coordination	
Type of Insurance	Percentage Reporting That a Professional Usually or Always Coordinates Their Child's Care
All Children	32.5
Public Insurance	40.5
Both Public and Private Insurance	34.3
Private Insurance Only	23.5

Source: MCHB, 2004.

The Idaho Families of Children with Special Health Care Needs Survey reported a much higher rate of care coordination usage. Nearly three quarters of parents who responded reported they used care coordination services in 2004. Medicaid was cited as the source of care coordination by most of those who received it, followed by the Infant Toddler Program, CSHP, and private care coordination companies. The discrepancy between the National Survey and the Idaho Survey likely is a result of the surveys drawing from a different pool of respondents. Most of the respondents to the Idaho Survey heard or received the survey through programs that their children participate in. These parents were more likely to have children with more serious conditions and more likely to be connected to services such as care coordination than those identified in the National Survey. Over 90 percent of parents in the Idaho survey said that it was very important for families of CSHCN to have information about what care coordination services are available and how to obtain those services.

Table VIII-18. Care Coordination Use	
	Percentage
Received Care Coordination	73.8%
Program or Agency Providing Care Coordination Among Those Who Received it	
Medicaid	43.0%
Infant Toddler Program	39.2%
CSHP	27.8%
Private Care Coordination Company	21.5%
Private Insurance	8.9%

Source: Idaho Families of Children with Special Health Care Needs Survey

Parents of CSHCN in the focus groups had mixed feelings about care coordination. They expressed a clear need for care coordination services, but had very mixed experiences with care coordinators. Many of them reported positive experiences with care coordination from the Infant

Toddler and CSHP Program, but experiences with Medicaid care coordinators were more mixed. A number of parents were unclear on what services these coordinators were supposed to provide. Some parents indicated that they did not find their advice useful and did not find them respectful so they stopped using their services.

CSHP Program. Many CSHCN with some of the most serious health conditions have been receiving some of their medical care through the Children's Special Health Program (CSHP). As noted earlier, CSHP has provided services to children with a limited number of conditions. Care has been provided through clinics that brought together multiple providers to provide treatment. The CSHP Program staff indicated that approximately 2,500-2,700 had been enrolled in the program and were eligible for care coordination services, treatment at the CSHP clinics, and reimbursement for services not covered by other sources. These numbers included an estimated 300 children who are uninsured and will be eligible for services under the new more limited CSHP Program. Table VIII-19 shows the number of children treated at clinics and by outside sources funded by CSHP in the year 2003. Data on who was receiving care coordination services was not available from the District Health Departments, but program enrollees who did not attend clinics could receive care coordination. In 2003, CSHP spent a little over \$224,000 on outside services for CSHCN. The costs of running the clinics included about \$600,000 in contract costs with local health districts and \$200,000 to reimburse doctors for travel and labor.

Table VIII-19. CSHP Program Usage, 2003		
Condition	Children Treated at CSHP Clinic	Children With Outside Services Paid for By CSHP
Cardiac	378	122
Cleft Lip and Palate	137	52
Craniofacial	49	22
Cystic Fibrosis	0	8
Neurological	63	41
Orthopedic	231	40
Phenylketonuria (PKU)	0	1
Plastic/Burn	0	6

Source: Idaho CSHP, 2004.

Most of the clinics operated by CSHP will continue under different auspices and many of the services previously funded under CSHP will be paid for under Medicaid for those families who qualify. However, this still remains a difficult transition. Because CSHP was available to cover services not covered under private insurance, the out-of-pocket expenses for parents who do not qualify for Medicaid may increase substantially. Both in the survey and the focus groups some

parents indicated that they had limited insurance coverage for their CSHCN because of the cost or because of plan limits. Additional out-of-pocket costs will be very difficult for many families to handle.

In addition, parents of CSHCN who participated in focus groups are concerned that the new clinics will not provide the same comprehensive care they received previously. Parents felt that the Health Districts did an excellent job organizing these clinics and are concerned that private providers will not be able to match that effort. Both parents and key informants from District Health Departments worried whether private providers would be willing to maintain the clinics over the long run.

Parents were also worried that while the medical care may still be available, the support services were likely to be more limited and care coordination will suffer. Part of this concern stems from mixed feelings about the quality of care coordination that is provided under Medicaid. While some parents had good things to say about the contracted care coordinators provided for their children under Medicaid, other parents reported very negative experiences. Care coordinators' experience with addressing the needs of the CSHCN population varied and it was not easy for parents to identify coordinators who were best suited for special needs children. It was not clear that all parents eligible even understand that they can obtain Medicaid care coordination services. Not all parents were given enough information to make informed choices about engaging a contracted care coordinator. There is a need for BOCAPs and Medicaid to examine this process and work to develop educational materials for parents and standards for care coordinators who are serving the CSHCN population. Medicaid staff agreed that consumer education on care coordination was needed, but the impetus for making progress in this area may need to come from another agency such as BOCAPs or the Division of Disabilities. Unfortunately, the Division of Disabilities has been given extremely limited resources for fulfilling their responsibility of quality assurance for care coordination.

Outcome 3: Families of CSHCN, including their siblings, have access to and use appropriately the full range of health and health-related services required to promote their growth and well-being and manage their conditions or disabilities.

Families of CSHCN need to be able to access a range of services without there being too high of a cost in terms of financial well-being and emotional strain.

Access to Quality Insurance Coverage. Families of CSHCN with high quality insurance coverage are able to access care with less strain on family finances. One of the MCHB Title V performance measures is that families of CSHCN will have adequate private and/or public insurance to pay for the services they need. As shown in Table VIII-20, the vast majority of Idaho CSHCN have some type of health insurance. The percent of uninsured children was only slightly higher than the 5.2 percent estimate for the country as a whole. In addition, to those who were uninsured at the time of the interview, an additional 6.4 percent of CSHCN experienced some gap in coverage during the year prior to the interview (MCHB, 2004). For parents of CSHCN, a gap in coverage can be an especially serious problem, because if it comes at a time when a child needs immediate care the family may find itself incurring extraordinary expenses.

The costs are likely to be high enough that the family may find itself in long-term debt with serious long-term impacts on the family's wellbeing.

Table VIII-20. Insurance Coverage for Idaho CSHCN	
Health Insurance Status	Percent
Type of Health Insurance for CSHCN	
Private insurance only	56.0
Public insurance	27.6
Both private and public insurance	10.3
Uninsured	6.2
Percent of CSHCN With No Gap in Coverage During the Year Prior to the Interview	87.4

Source: MCHB, 2004

Hispanics are the most likely of any racial/ethnic group to be uninsured at the time of the survey. Hispanics and those classified as "Other race/ethnicity" were more likely to rely on public insurance, though more than one-third of Whites either have public insurance alone or in combination with private insurance. Medicaid and SCHIP are crucial resources for families of CSHCN, and the quality of services they provide are critical in achieving positive outcomes for these families. While their relatively low incomes are probably one cause of the lack of insurance among Hispanic families, another possibility is that eligible Hispanic families are not applying because they do not understand the eligibility rules. Hispanic immigrant parents may not realize that their U.S.-born children may be eligible regardless of their own citizenship status.

In the Idaho Families of Children with Special Health Care Needs Survey over 90 percent of respondents indicated that it was very important for families of CSHCN to have information about how to apply for Medicaid and what benefits are covered under Medicaid. While the 'other race/ethnicity' group was not more likely than Whites to be uninsured at the time of the survey, they did not report a high rate of uninsurance over the course of the year. The small sample size of uninsured 'other race/ethnicity' families made assessments of coverage in this group impossible. However, this small sample size does raise some concern that people may be coming on and off Medicaid and SCHIP on a regular basis and thus experiencing periods without coverage.

The poorest families were not the most vulnerable due to a lack of insurance. Families just above the poverty level were three times as likely as those under the poverty level to be uninsured. Almost one-quarter of these families were uninsured at some point during the 12 months prior to the survey (MCHB, 2004). These families almost always include at least one working adult and are struggling to play by the rules, but are denied access to a critical resource.

Table VIII-21. Insurance Coverage by Race/Ethnicity and Income					
Characteristic	Insurance Status				
	Private	Public	Both Public and Private	Uninsured at the time of survey	Uninsured during past 12 months
Race/ethnicity					
White	58.3	25.6	10.6	5.4	10.6
Hispanic	38.3	40.2	3.5	18.0	27.5
Other	35.0	47.2	11.4	6.4	30.9
Income					
0-99 percent of the Federal Poverty Level (FPL)	11.1	75.0	9.9	4.0	13.0
100-199 percent of FPL	39.3	38.9	9.7	12.2	23.7
200-399 percent of FPL	80.0	5.8	10.4	3.9	7.8
400 percent of FPL	88.7	1.4	9.2	0.8	2.4

Source: MCHB, 2004

Respondents were asked whether their insurance was meeting their child's needs. While most respondents reported that their insurance coverage was meeting their child's needs, there were quite a few respondents for whom this was not the case. One of the biggest challenges faced by parents was the cost of care not covered by insurance. About one-third of respondents reported that these costs were never or only sometimes reasonable.

Table VIII-22. Adequacy of Insurance Coverage for Idaho CSHCN	
Characteristic of Insurance Coverage	Percent of Insured Children
Insurance usually or always met child's needs	84.2
Insurance usually or always permitted child to see needed providers	85.4
Costs not covered by insurance were usually or always reasonable	66.4

Source: MCHB, 2004

The type of insurance did not make a difference in whether health insurance usually or always met child's needs, but participants on Medicaid were more likely to characterize their health plan

as good for CSHCN. Participants in the focus groups indicated that some of the strong points of Medicaid were low out-of-pocket costs and more assistance with care coordination than private insurance.

Table VIII-23.			
Type of Insurance by Adequacy of Insurance			
Adequacy of Insurance	Type of Insurance		
	Private Insurance	Public Insurance	Both Private and Public Insurance
Percent indicating insurance usually or always met child's needs	83.8	85.0	87.0
Percent indicating insurance is good for CSHCN	71.8	89.0	90.4

Source: MCHB, 2004

While there are a number of positive aspects of having Medicaid for CSHCN, there are also some important challenges that families face in accessing and using Medicaid. In the Idaho Families of CSHCN survey 34.9 percent of families reported that they needed more information about what services were covered under Medicaid, while another 22 percent reported that they needed much more information about this. This topic came up during the focus groups with parents reporting that it was often unclear what services and equipment were covered and it was difficult to obtain a direct answer on these issues from the Medicaid office.

Parents of CSHCN in the focus groups described great difficulty finding out about, applying for, and maintaining benefits under the Katie Beckett provisions of Medicaid. Katie Beckett Medicaid is available to families who, if they did not have Medicaid, would have to put their child in residential care because the child requires costly in-home care. Because the child would be living outside the home without Medicaid, the child's income and assets are counted when determining eligibility rather than the other household members. Quite a few parents reported that Medicaid eligibility workers were unaware of the rules for Katie Beckett Medicaid and were unable to assist them with applying. Parents reported a great fear of losing Medicaid when it came time to reapply because of administrative reasons or because of slight changes in their child's condition. One parent of a foster-child with special needs indicated that her family maintained burdensomely expensive catastrophic health care coverage for the child because she had been told that a change in the child's condition could possibly result in them losing Katie Beckett Medicaid coverage. Other families reported losing coverage because of what appeared to be administrative problems. The result of these problems is that families are under tremendous strain, feel financially vulnerable, and do not feel the system exists to help them. Medicaid could alleviate some of these problems by training specific workers or supervisors to specialize in these cases. The laws and regulations governing Katie Beckett Medicaid are indeed complex and it may not be reasonable or efficient to expect all eligibility workers to be able to apply them. However, in order to provide a reasonable level of customer service and support for families in difficult circumstances, it would be useful to have workers specifically trained to handle these cases in regional and State administrative offices.

Financial Strain. Having a child with special needs is often a considerable financial burden that strains a family's resources and creates additional stress. More than one-quarter (27.6 percent) of families of CSHCN report that their child's condition has caused financial problems for the family (MCHB, 2004). The financial burden differs by the level of severity of the child's illness as shown in Table VIII-24.

Table VIII-24. Percent of Respondents Indicating that their Child's Condition has Caused Financial Problems for Their Family by Severity of Child's Condition	
Severity of Child's Condition	Percentage Reporting Financial Problems
Mild	15.8
Moderate	28.1
Severe	40.5

Source: MCHB, 2004

The parents of CSHCN who participated in the focus groups elaborated on the financial burdens they face. Many of those with private insurance had to contribute substantial co-payments in order to provide for their children. Others indicated that there had been a time when they were without insurance and that they have never been able to fully recover financially. A number of them described being pursued by debt collection agencies. Parents in these groups have varying knowledge about how the health system works and while some reported that they were able to convince hospital billing departments that their debt should at least be partially written off as charity care, others were unaware that such a possibility existed. While it is impossible to fully alleviate the strain of raising a child with special needs, efforts to organize services and ensure access to available benefits with minimal hassle can help limit the stress on the family. Having someone available who can discuss options when financial burdens become too great would also be helpful.

Family-centered Care. Another MCHB Title V outcome is that families of CSHCN partner in decision-making and are satisfied with the care they receive. There are a number of questions on the National Survey of CSHCN which address whether doctors delivered family-centered care. The results shown in Table VIII-25 generally indicate that most families report positive experiences with their doctors.

Table VIII-25. Indicators of Family Centered Care	
Doctors usually or always spent enough time	84.4%
Doctors usually or always listened carefully	87.0%
Doctors were usually or always sensitive to values and customs	85.9%
Doctors usually or always provided needed information	80.5%

Source: National Survey of CSHCN

Hispanics were less likely than Whites or those of other races/ethnicities to agree that doctors usually or always provide family-centered care. This may be because doctors who provide services to the Hispanic community are more in demand and have less time for individual patients, or it may be that some doctors have failed to develop culturally sensitive practices.

Table VIII-26.			
Indicators of Family Centered Care By Race/Ethnicity			
Indicator	Race/Ethnicity		
	White	Hispanic	Other
Doctors usually or always spent enough time	86.2	66.8	71.7
Doctors usually or always listened carefully	87.7	79.9	81.2
Doctors were usually or always sensitive to values and customs	86.5	75.7	86.2
Doctors usually or always provided needed information	81.1	67.3	77.8

Source: MCHB, 2004

In general, families of CSHCN in the focus groups were usually satisfied with the medical care they received. Some of them did report negative experiences with doctors or health care professionals who questioned why they were investing so much energy in what the professional saw as a helpless case. But overall the quality of care, especially that provided by specialists, did not seem to be the big concern. What was far less family-centered was the ability to obtain approval for care, especially non-medical services such as physical and occupational therapy.

Community-based Services for Families of CSHCN. Another Title V performance measure is that community-based service systems will be organized so that families can use them easily. Three-quarters of respondents to the National Survey of CSHCN reported that community-based services were usually or always organized so that families can easily use them (MCHB, 2004).

This relatively positive perception contrasts with the views of parents of CSHCN who took part in the focus groups. These families reported an almost complete lack of supportive services for families of CSHCN. These families are under tremendous stress, but lack access to assistance to relieve the strain. Families indicated that respite care benefits were inadequate and that it was very difficult to find anyone to watch special needs children for the amount that is paid. Transportation reimbursements of \$0.10 per mile do not nearly cover costs. The process of obtaining reimbursement was considered burdensome and further discouraged parents from utilizing this resource. There needs to be recognition that these families spend tremendous amounts of time seeking and managing care for their children. When unnecessary difficulties are created in obtaining assistance, they must weigh the costs in additional time with their other obligations. Other families, especially those who delivered special needs children in Salt Lake City, reported that when they had their special needs child they were simply not given enough information about what was available and what they needed to do once they arrived home. While it was helpful to have been given the number for the Infant Toddler Program, it would have been more helpful to have been given a better sense that they would have some support available once the child arrived home. In the Idaho Families of CSHCN survey almost 93

percent of families cited access to ongoing up-to-date information about programs, services and eligibility as a very important support service. Families in the focus groups indicated that it was more of a struggle to obtain information on what was available and what needs to be done to access services than it should be.

Parents did identify a few places where they were able to find positive support and information. St. Luke's in Boise offered a wide range of supportive services along with access to parent support groups for families whose children are hospitalized. A few of the parents had developed their own support groups while some relied on internet-based support groups for children with conditions similar to theirs. Parent groups are able to provide a level of support and information that is otherwise lacking. Even during the focus groups, parents were updating each other on changes in programs and providing suggestions for finding services. One way the MCH agency can fulfill its mandate to help the CSHCN population is to provide support to encourage the creation of parent groups and the training of parents as peer advocates who can work with other families with CSHCN. Most parents who received services from the Infant Toddler Program reported positive experiences with those services. This also is the program that is cited as being most open to parental input and participation. It is likely that these two findings are linked and that other programs need to make similar efforts to welcome parent participation in program development and service delivery.

Outcome 4: CSHCN use out of home childcare, preschool, and ongoing educational services as appropriate to their age, developmental stage, and health condition and/or disability.

The needs of CSHCN change throughout their lifetime and it is important they have access to services that foster their development. There are a number of agencies that have lead responsibility for providing these services; connections between these agencies and other providers are essential to ensuring that CSHCN have access to early education and development services.

Inclusive Child Care. Like all families, families of CSHCN often need child care services. However, families of CSHCN face extra challenges in finding a qualified and affordable provider. The Idaho Department of Health and Welfare recognizes that there are very limited child care options for CSHCN. The Department commissioned a paper from the Center on Disabilities and Human Development (CDHC) at the University of Idaho to look at options for Promoting Inclusive Child Care in Idaho. The subsidies offered by the Idaho Child Care Program are clearly inadequate for CSHCN. While some children participate in Infant Toddler or pre-school special education programs, these tend to only be for a few hours each day. Children may receive Medicaid-funded developmental therapy services from a Developmental Disabilities Agency (DDA) Provider, but these services are not generally provided at child care settings (Center on Disabilities and Human Development, 2004). The Idaho Child Care Program, the Division of Medicaid, CDHC and the Idaho Association for the Education of Young Children (IAEYC) have formed a task force to discuss options for improving access to child care, including ways to make it easier for child care providers to qualify as DDAs and thus obtain reimbursement for providing developmental therapy.

The Infant Toddler Early Intervention Program. The Infant Toddler Early Intervention Program appears to provide a good start for CSHCN who are identified in the first three years of life. Focus group participants and key informants generally had a good impression of the program. Some focus group participants expressed regret over the change from center-based to natural environment settings for care. Parents of older children reported positive experiences in Infant Toddler centers and these centers also offered a setting where parents of CSHCN could connect with each other. However, regardless of these concerns, most parents reported positive experiences with the care coordination and other services offered through the Infant Toddler Program. The Regional Interagency Coordinating Councils were reported to be a positive source of collaboration and the program was credited with welcoming parent involvement.

The “child find” function, which involves trying to identify children eligible for the Infant Toddler Program, is formally the responsibility of the Health District offices. However, focus groups and key informant interviews indicated that other organizations such as Head Start also conduct developmental assessments. A number of parents in the focus groups which included mostly parents of typical children felt that these assessments were not well publicized and their purpose was not always explained. The Infant Toddler Program is also responsible for the Developmental Monitoring Program. This is another effort to identify children in need of services. Parents are sent copies of the Ages and Stages Questionnaire (ASQ) and the completed forms are reviewed by the Health District offices. The District offices are responsible for making referrals when warranted. The Program Director reported that 5,500 ASQs are sent out annually under this initiative. There is not enough information to judge the success of this effort on a statewide basis, however concerns were raised by parents in District 2 because the questionnaires were arriving late and were no longer appropriate for the age of the child in the household. On the other hand, it was also reported that the wide distribution of the ASQ has served to educate parents and providers about what constitutes developmentally appropriate behavior. This may result in increases in self-referrals.

Key informants indicated that educating physicians and hospitals to make referrals into the infant and toddler program is a challenge. Physicians are currently responsible for about 18 percent of referrals, hospitals 17 percent, family and friends 25 percent, public health facilities 20 percent and other social services approximately 7 percent. On the state level, a few years ago the Infant Toddler program engaged in a blitz of training activity for physicians and saw an increase in referrals from physicians. However, the numbers have decreased again. In Pocatello, a Children’s Special Health Program Task Force was formed with partners including the District Health Department, the Regional Health and Welfare Office, two regional medical centers, Idaho State University, and Idaho Parents Unlimited, a parent advocacy organization. One of the goals was to identify and refer children for needed services. As a result of this effort the percent of referrals from primary care physicians rose from 16 percent to 26 percent. (Early Intervention Research Institute, 2001). These experiences clearly indicate that physician behavior can be changed, but that ongoing efforts are needed to reinforce the changes.

Once a child is identified they can receive a wide array of services under the Infant Toddler Program. On June 1, 2004, the Infant Toddler Program was serving 320 children ages birth to one and 1,576 children ages birth-3. The target goal is to enroll at least 1 percent of all children ages birth to one and 2 percent of children ages birth to three. Overall the State is meeting those targets, though at various points some regions have struggled to achieve them. Region IV, which

includes Boise, was not meeting the target for infants and over the last few years has regularly failed to meet the 2 percent target for all eligible age groups. In fact, the available data which goes back to 1998 shows that June 2004 was the first time they had met the 2 percent target. The Part C Annual Performance Report attributes this to rapid population growth in the region, combined with staff shortages that limit the extent of outreach and child find activities.

Table VIII-27. Enrollment in the Infant Toddler Program by Age Group and Region, June 1, 2004		
Region	Age Group	
	Birth-1	Birth-3
Region 1	1.26	2.25
Region II	1.93	2.82
Region III	2.05	2.89
Region IV	0.92	2.05
Region V	2.43	3.04
Region VI	1.13	2.76
Region VII	1.63	2.49
State	1.53	2.49

Source: Idaho Infant and Toddler Program, 2004.

Another possible source of under-participation in the Infant Toddler Program in Region IV is apparent from an examination of enrollment data by race and ethnicity. As shown in Table X-27, for most regions the percent of Hispanics enrolled in the program is higher than the percent in the population. This is to be expected since Hispanic families in Idaho exhibit more risk factors, such as poverty and lack of health insurance. However, in Region IV, the share of Hispanic enrollment is equal to the share of the Hispanic population of the region. Another area of concern is Region I, which has a lower share of both Hispanics and American Indians enrolled than might be expected given the two groups share of the population in these regions. Similarly, Regions 3 and 5 also have low enrollment for the American Indian population, especially in relation to Region II. While it is impossible to say what the ideal proportion of each population group should be enrolled in the Infant Toddler Program, the discrepancies between regions suggest an area that warrants further investigation. Some regions may have developed very successful outreach and child find efforts with specific populations that can be shared with others. It is very important that all agencies and organizations come together to ensure that children in this age group in need of services obtain those services because this may help head off future problems.

Table VIII-28. Enrollment in Infant Toddler Program by Race/ethnicity and Region “Cumulative” Count Data for Program Participants, May 31, 2003 thru June 1, 2004						
Region	White		Hispanic		American Indian	
	Percent Enrolled	Percent of Population	Percent Enrolled	Percent of Population	Percent Enrolled	Percent of Population
Region 1	98.2	97.3	0.7	2.3	0.7	1.9
Region II	82.9	94.8	2.1	2.0	13.4	3.4
Region III	68.3	97.0	30.4	17.7	0.2	1.3
Region IV	89.8	95.5	5.6	5.6	0.5	0.9
Region V	75.2	97.9	23.6	15.7	0	1.0
Region VI	83.4	94.8	11.0	8.0	3.7	3.8
Region VII	82.1	97.9	14.7	7.5	1.1	0.7
State	81.9	96.4	14.4	8.5	1.8	1.6

Source: Idaho Infant and Toddler Program, 2004.

There are data that raise some interesting questions about collaboration between the Infant Toddler Program and other programs that serve CSHCN. As shown in Table VIII-29, there are vast differences in the percent of children enrolled in the Infant Toddler program who also participated in the CSHP program and who are involved with the Bureau of Children and Family Services or child protection agency. It is possible that some of these differences may reflect differences in data collection efforts in the regions, but regardless of data issues they also likely reflect regional differences in the level of collaboration between programs.

Table VIII-29. Enrollment in the Infant Toddler Program by Involvement With Other Programs and Region, May 31, 2003 thru June 1, 2004		
Region	Other Program Involvement	
	CSHP Enrolled	CFS Enrolled
Region 1	2.9%	6.8%
Region II	2.1%	36.1%
Region III	1.1%	11.4%
Region IV	4.9%	5.4%

Table VIII-29. Enrollment in the Infant Toddler Program by Involvement With Other Programs and Region, May 31, 2003 thru June 1, 2004		
Region	Other Program Involvement	
	CSHP Enrolled	CFS Enrolled
Region V	8.3%	12.7%
Region VI	7.2%	9.1%
Region VII	16.6%	6.0%
State	6.4%	9.5%

Source: Idaho Infant and Toddler Program, 2004.

Collaboration between the Infant Toddler Program and the Bureau of Children and Family Services will be of increasing importance. As a result of changes in Federal regulations, the Infant Toddler Program will need to begin doing a developmental assessment on all children where there is a substantiated case of abuse or neglect. Implementation of this provision is a major challenge for program staff who have not generally been responsible for conducting mandatory assessments. In addition, adding additional responsibilities in the face of limited staffing is a real concern. Ideally, child protection workers can be trained to conduct developmental assessments, but at this point in time responsibility will be in the hands of Infant Toddler Program staff.

Special Education Services. At age 3 children who have disabilities or delays are no longer eligible for the Infant Toddler Program. They may qualify for special education services provided by school districts. It is important that students who receive Early Intervention Services have their eligibility for Special Education Services assessed. The State has done an admirable job in ensuring that this occurs. In 1998-1999, 170 children exited the Infant Toddler Program without being assessed for eligibility for Special Education. In 2001-2002 the total was 7 children then in 2002-2003 it was 11 children, and the most recent data show an increase to 24 children (Idaho Infant Toddler Program, 2004). Progress in originally reducing the number not assessed was attributed to an interagency grant-funded effort to address the issue. Having a performance measure for both the Infant and Toddler Program and the Special Education Program that focused on the number of children not assessed was also cited as a key factor in focusing attention on this issue. The recent rise has raised concerns and both agencies report that they will take steps to address this increase.

According to the Idaho 2002-2003 Part B performance report, about ten percent of children ages 3-21 were receiving services through Special Education in 2003-2004 (Bureau of Special Education, date unknown). The U.S. Department of Education reports that about 11.7 percent of the total enrolled student population had an Individualized Education plan at some point during 2001-2002. The U.S. Department of Education provides comparisons between States based on the December 1 count of participants which does not include students who may enter the program after that day or leave before that date. In these data, 9.7 percent of the Idaho age 6-17

population and 6.3 percent of the age 3-5 population were receiving Special Education services in December 2003. This compares with 11.5 percent of the age 6-17 population and 5.8 percent of the age 3 to 5 population for the 50 States and the District of Columbia (Office of Special Education Programs, 2004).

The number of special education students ranged from 21 in Camas County to 5,937 in Ada County.² Seven counties have over 1,000 special education students and 15 counties have at least 500. The percent of children enrolled in school with an IEP by county is shown in the map. The percentage ranges from 9.7 percent in Boundary County to 17.6 percent in Custer County. Differences between counties may be due to a variety of factors. Some of the differences may reflect differences in the population's needs, but other factors include what tools are used to identify special education children and what alternatives exist to special education services in the county. One of the concerns that the Department of Education has been addressing is that some school districts have used assessment tools that are invalid when used on immigrant students. Some of these school districts may be classifying children as special education students because they do not have programs to address the needs of students for whom English is not a native language.

² Idaho has 113 school districts so many counties have more than one school district.

Figure VIII-1: Percent of School-Aged Children in IED Programs

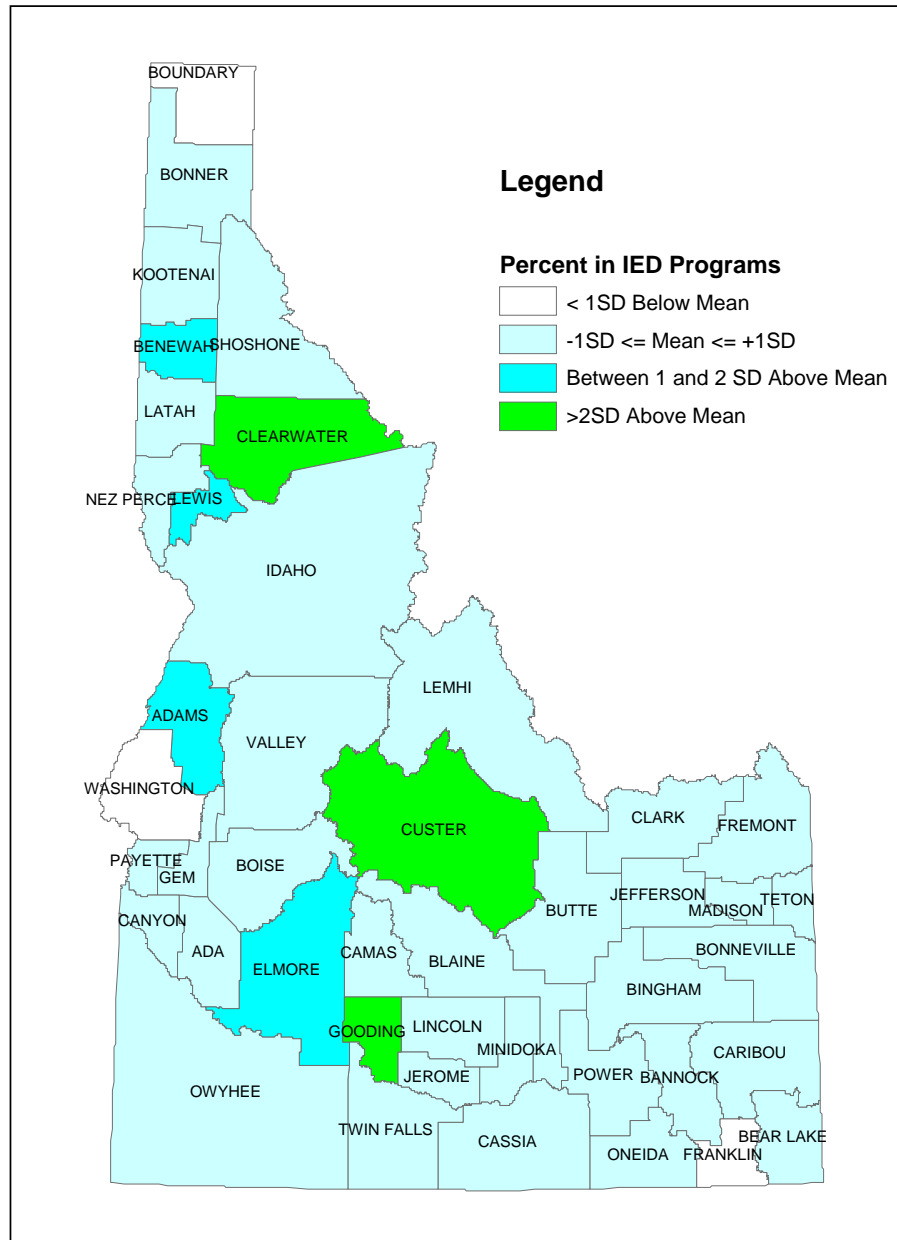


Table VIII-30 shows the reasons students are placed in the special education category. The most common reason for all children is that they are classified with a learning disability. For preschool children, learning disability is a rarely used category; instead, developmental delay is most common. Speech impairments are the second most common classification for both age groups. A key informant noted that the emotional disability classification may be underreported because schools are reluctant to use such labels with young children.

Table VIII-30. Students Served By Special Education by Age Group and the 10 Most Common Disability Categories			
Primary Disability	Age Group		
	Ages 3-5	Ages 6-21	All Eligible Ages
Learning Disability	0.6	50.1	43.6
Developmental Delay	58.7	6.0	12.9
Speech Impairment	24.4	9.8	11.7
Language Impairment	9.8	8.4	8.6
Cognitive Impairment	0.4	6.8	6.0
Health Impairment	1.2	6.5	5.8
Emotional Disability	0.1	4.6	4.0
Autism	1.7	2.2	2.2
Multiple Disabilities	1.0	1.8	1.7
Noncategorical Eligibility	0.4	1.2	1.1

Source: Bureau of Special Education, 2004.

Special education students receive an average of 1.7 services per child. This ranges from a low of 1.3 services per child for children classified with a speech impairment to 4.2 services per child for those classified with multiple disabilities. Table VIII-31 shows the percent of children receiving particular services by their primary disability. It should be noted that very limited family support services are provided. The percentage of students receiving family support services ranges from no deaf and deaf-blind students to 4.2 percent of emotional disabled students. The fact that these numbers are low is not surprising since school districts focus their limited resources on students. It does however speak to the need for special education programs to have connections with other service providers or family networks that can step in and provide needed services and support.

Table VIII-31. Percentage of Students Receiving Specific Services By the 10 Most Common Disability Categories					
Primary Disability	Percent of Students Receiving Specified Service				
	Speech Service	Language Service	Occupation al Therapy	Physical Therapy	Counseling
Learning Disability	17.8	30.6	7.8	1.2	3.0
Developmental Delay	21.7	29.2	13.2	5.8	0.6
Speech Impairment	70.6	9.5	2.0	0.5	0.1
Language Impairment	18.6	57.4	4.1	0.7	0.4
Cognitive Impairment	15.1	24.7	11.4	3.7	0.7
Health Impairment	13.0	18.6	16.0	7.8	4.1
Emotional Disability	4.7	5.9	2.1	0.1	17.3
Autism	12.2	26.5	15.8	3.5	0.7
Multiple Disabilities	9.6	15.3	15.4	12.2	0.3
Noncategorical Eligibility	19.1	26.1	7.0	2.3	0.9

Source: Bureau of Special Education, 2004.

The Bureau of Special Education and Medicaid have worked closely to enable school districts to become Medicaid providers and to bill Medicaid for services covered under the program. As a result, Medicaid spending on school district services has increased from \$1.9 million in FY 2001 to \$6.6 million in FY 2004. Idaho Fiscal Facts 2004 estimates that this upward trend will continue and that total charges for school district services under Medicaid will reach \$19.9 million by FY 2006. (Idaho Legislative Services Office, 2001 & 2004).

Parents in the focus groups reported vastly uneven experiences with the special education program for preschool and school-aged youngsters. While some parents were able to obtain services or have their child transferred to an alternative school setting, many more reported great difficulties in obtaining special education services. School districts offered strictly limited levels of physical and occupational therapy. Obtaining services often required a protracted battle with the school system. One of the main problems key informants cited with special education in Idaho is the extremely high caseload of special education teachers and other providers. In the 2002-2003 school year, Idaho had a ratio of 26 students per teacher providing special education. This ratio has been in the 25-26 range since the 1998-1999 school year. This compares with a ratio of 18 students per special education teacher for the nation as a whole the last year national data were available (1999-2000 school year). (Bureau of Special Education, Unknown B) The teacher shortage reflects budgetary limitations and difficulties retaining qualified teachers. The

State Department of Education conducted a survey of teachers leaving Special Education and found that the top two reasons for leaving were the amount of paperwork and the size of the caseload. It is unclear whether Idaho can address the quantity of paperwork per student issue since much of it is probably driven by Federal requirements, but the State clearly has more control over enrollment per teacher.

Rural school districts also face a real challenge obtaining the range of services needed by CSHCN and retaining teachers and staff. A few school districts have joined together to provide services. Five small school districts in southwestern Idaho have joined their Special Education programs into a single cooperative administration that has responsibility for Special Education budgets and services across districts. The State Department of Education has worked with the District to ensure that they are able to do this while complying with Federal regulations. This type of cross-district collaboration would appear to have great promise in a rural State like Idaho. There are real challenges in terms of gaining cross-district agreement and some similar arrangements have broken up over time, but it is clearly one way to enhance the level of services.

Transition to Adult Life. The final Title V performance measure for CSHCN states that youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence. Idaho, similar to most of the rest of the country, has struggled to provide the services necessary to help CSHCN transition to adulthood. In the Idaho Families of CSHCN Survey 49 percent of parents reported needing much more information about services available to prepare for their child's transition to adulthood. Among the types of information that were asked about, the only type of information more parents needed much more information about was Katie Beckett Medicaid. Some of this may reflect that only 24.1 percent of respondents had CSHCN age 13 or over. However, National CSHCN survey data and comments from parents in the focus groups indicate that there is a great deal of room for progress on this performance measure.

As shown in Table VIII-32, the National Survey of CSHCN indicates that doctors have talked about the changing needs of CSHCN as they become adults for only half of the CSHCN over age 13. In even fewer cases is there a plan for addressing the child's changing needs. Among all CSHCN over age 13 in Idaho, 20 percent have received vocational or career training.

Table VIII-32. Transition to Adulthood (for children ages 13 and older)		
	Idaho	United States
Doctors have talked about changing needs as child becomes adult	50.2	50.0
There is a plan for addressing the child's changing needs	28.4	30.3
Child has received vocational or career training	19.6	25.5

Source: *MCHB, 2004.*

The picture is brighter in terms of transition assistance if you look at high school graduates. About three-quarters of graduates report that their high school has connected them to employment, college or community agencies such as vocational rehabilitation. However, this and other data shown in Table VIII-33 reveal why transition issues are a major concern for the special education program. There has been no increase in the number of students reporting assistance with transitions and both employment and post-secondary enrollment are lower for the Class of 2002 compared to the Class of 2000. Transition issues are a big concern for the Special Education Program. The State is taking a number of steps to improve this situation and the Idaho Interagency Coordinating Council is in the process of finalizing interagency agreements, including roles and responsibilities in transition planning.

Table VIII-33. Indicators of Successful Transition to Adult by Year of Graduation			
Indicator of Successful Transition to Adulthood	Year of Graduation		
	Class of 2000	Class of 2001	Class of 2002
Special Education students reporting that their high school connected them to a job, college, or community agency	75	76	74
Post Secondary Enrollment			
Special Education Students	24.5	18.4	20
All Graduates	47.8	47.6	48
Special Education students employed one year after graduation	66.2	64.6	58.5

Source: Bureau of Special Education, Unknown B.

C. Summary Findings and Analysis

Idaho CSHCN Outcomes

CSHCN Outcome 1: Children with chronic health problems or disabling conditions use all the primary and preventive services used by typical children.

Summary

- Less than two-thirds of CSHCN reported needing routine preventive care in the 12 months prior to being surveyed. A larger proportion of families reported needing dental care.
- Hispanic families were less likely to report that their CSHCN needed primary and preventive services than white families.
- Low income families and those who were uninsured or received publicly-funded health insurance were less likely to report needing dental care.
- Most families who reported needing preventive and primary care for their CSHCN were able to obtain care. For those who were unable to obtain care, the most common reason for not being able to do so is the cost of the care.

Analysis

- Families of CSHCN are similar to families of typical children in not always seeing the value of primary and preventive care for their children. Efforts to encourage the use of such care should include families of CSHCN.
- While families of CSHCN who say their child needs primary and preventive care are generally able to access it, decisions about what constitutes need are likely based on calculations that take into account the seriousness of condition, the cost of the care, and the ability to access services. Hispanic families and low-income families are likely deferring care because of affordability and access issues. Efforts to improve their access to primary and preventive care, especially including dental care, are important for preventing more serious health problems.
- Being unable to afford preventive care is the primary barrier to not receiving it. Low cost alternatives such as Community Health Centers and Health District immunization programs represent a key pillar in promoting use and access. It is essential that these services be supported and well publicized among all communities.

CSHCN Outcome 2: CSHCN use the full range of health-related services needed to maintain their health and well-being and the services to slow, delay, or prevent untoward outcomes resulting from their chronic health conditions or disabilities.

Summary

- Other than primary and preventive care, the most common type of care needed by CSHCN is prescription medicine, followed by care from a specialty doctor, medical supplies, and physical, occupational or speech therapy.
- CSHCN were mostly able to obtain the most commonly needed types of care.
- Mental health care or counseling was reported being needed by 15 percent of CSHCN families and was the type of care that most families (25 percent of those needing it) had difficulty accessing.
- The most common reason for not being able to access services beyond primary and preventive care was that it costs too much. However, for mental health care or counseling

Idaho CSHCN Outcomes

and genetic counseling a lack of available providers appears to be a problem. For physical, occupational or speech therapy (26 percent of those needing care) and mental health care or counseling (17 percent of those needing care) problems with health plans were also reported by a considerable number of families.

- Problems obtaining a referral for specialty care were experienced by 18 percent of families and more than one-third of families who had a CSHCN with a serious condition and 27 percent of those enrolled in publicly funded health insurance.
- Most families report having a usual source of care for their CSHCN though it is less common among Hispanic families.
- Good communication between doctors is somewhat uncommon and good communication between doctors and other programs is even more uncommon.
- The extent to which families of CSHCN use care coordination is somewhat unclear. Evidence from the Idaho survey and focus groups indicate that the service is used and very much appreciated when it is of high quality. Privately insured families are far less likely to use care coordination or have it available.
- The changes in the CSHP Program will impose great difficulties on families who have insurance but were able to use the program to pay some of their out-of-pocket costs. CSHP families are also concerned about a quality and comprehensive service now that the clinics and care coordination responsibilities are being shifted from the local Health District offices.

Analysis

- Access to mental health care providers and physical, occupational, and speech therapy are difficult issues for families. The State may want to examine efforts to improve access elsewhere for ideas that go beyond current initiatives (i.e., Children's Mental Health Councils). For example, Iowa has had some success using telemedicine to provide mental health services in rural areas.
- The State should reconsider whether Healthy Connections is appropriate for CSHCN with serious conditions. It is unclear that the program is meeting its cost containment goals for these families and it may be imposing an unnecessary burden on them.
- Quality care coordination is a useful service for CSHCN. The care coordination system offered through Medicaid needs to be strengthened so that at least some care coordinators are better trained in working with CSHCN families. Families of CSHCN should be able to easily tell which coordinators have experience working with such families, so some type of certification system may be needed.
- The CSHP Program could not continue as it had given the size of the budget. Efforts have been made to ensure that some of the services are continued using other resources. This change is extremely difficult for parents who participated in the program, especially those with private insurance who now face a substantial increase in out-of-pocket costs. Efforts continue to be needed to provide support for former CSHP families and for the broader CSHCN population. The existing care coordination system needs to be strengthened to ensure that communication among programs, providers, and parents is effective and that there is some way of identifying families who need assistance because they simply cannot afford the cost of needed care.

Idaho CSHCN Outcomes

CSHCN Outcome 3: Families of CSHCN, including their siblings, have access to and use appropriately the full range of health and health-related services required to promote their growth and well-being and manage their conditions or disabilities.

Summary

- 6.2 percent of CSHCN in Idaho were without insurance at the time of the National Survey of CSHCN. 12.6 percent were without insurance at some point during the year prior to the survey.
- More than one-quarter of Hispanics and non-white CSHCNs were without insurance at some point during the year prior to the National Survey of CSHCN.
- The income group at greatest risk of being without insurance is CSHCNs whose family income is just above the Federal poverty level. More than 12 percent of these families were uninsured at the time of the National CSHCN Survey and almost 24 percent were uninsured at some point during the year prior to the survey.
- Over 84 percent of families of CSHCN with insurance say that the insurance meets their needs though one-third of these families indicate that out-of-pocket costs were frequently unreasonable.
- Medicaid is considered better insurance for CSHCNs than private insurance.
- More than one-quarter of families of CSHCN experience problems because of costs associated with their child's condition. This rises to over 40 percent of families when the child's condition is rated as severe.
- Most families have positive things to say about the quality of care doctors provide to CSHCNs though about one-third of Hispanic families report that doctors often do not spend enough time with their child and often do not provide needed information.
- About one-quarter of respondents to the National Survey of CSHCN reported that community services were not usually organized in a way that made them easy to access. This opinion was both more common and stronger among focus group participants and those participating in the Survey of Idaho Families of CSHCN.

Analysis

- Lack of health insurance is a problem for a considerable number of families with CSHCNs. The percent of Hispanic families who lack insurance at least part of the year is especially a big concern.
- Efforts should be made to ensure that families of CSHCN are not losing Medicaid because of administrative reasons. Even short periods of time without insurance can be financially devastating for families of CSHCN if it is during a period when their child needs extensive care.
- There is need for outreach directed at Hispanic families who may assume they are ineligible for Medicaid because of their citizenship status, but whose children are eligible by virtue of being born in the U.S.
- Families of CSHCN need more input into how community services are organized. The Infant Toddler Early Intervention Program's efforts in this regard may serve as a model for the broader system of services for CSHCN.

Idaho CSHCN Outcomes

CSHCN Outcome 4: CSHCN use out of home childcare, preschool, and ongoing educational services as appropriate to their age, developmental stage, and health condition and/or disability.

Summary

- It is difficult for Families of CSHCN to obtain child care.
- The Infant Toddler Program serves 2.5 percent of all Idaho children ages Birth to Three and 1.5 percent of Idaho's infants.
- Participation rates in the Infant Toddler Program vary by region. Region V has the highest participation rates while Region IV has the lowest participation rates.
- The proportion of Hispanics enrolled in the Infant Toddler Program exceeds the proportion of Hispanics in the population in Regions III, V, VI and VII. In Region I Hispanic participation rates are lower than proportion of Hispanics in the population and the two numbers are close to equal in the other regions.
- American Indians make up a larger share of participants than their share of the population in Region II. In other regions they are either underrepresented or the proportion in the Region's population is close to the proportion participating in the program.
- Data show vast differences in the percent of Infant Toddler Program participants who are involved with the State child protection agency and CSHP. Some of this may reflect differences in data collection, but it also likely reflects different levels of collaboration between programs.
- Families and friends are responsible for about one-quarter of referrals into the Infant Toddler Program, public health 20 percent, physicians 18 percent, and hospitals 17 percent.
- The State has successfully reduced the number of children exiting the Infant Toddler Program without being assessed by the preschool special education program.
- About 10 percent of Idaho's children age 3-21 receive special education services. Idaho's participation rate is lower than average for children ages 6-17 and a little higher among the preschool group.
- Special education enrollment varies tremendously by county.
- More than half of preschool special education students are classified as having a developmental delay and more than half of the age 6-21 group are classified as learning disabled.
- Speech, language, and occupational therapy are the most common services provided to students in the special education program.
- In recent years more school Special Education programs have become Medicaid providers and Medicaid spending on school related services has increased from \$1.9 million in FY 2001 to \$6.6 million in FY 2004.
- Idaho has struggled to meet requirements to help Special Education students and CSHCNs with the transition to adulthood.

Idaho CSHCN Outcomes

Analysis

- Medicaid, the Child Care Program and advocates for the developmentally disabled community have developed a Collaborative Task Force to study ways to promote inclusive child care in Idaho. This approach shows great promise. Medicaid has been a very forthcoming partner in helping the Special Education Program work with schools to become Medicaid providers and a similar approach with child care providers has the potential to make progress on this important issue.
- Differences across regions in participation in the Infant Toddler Program raise some important concerns. While it is hard to say what percentage of Hispanics or American Indians should be participating, more risk factors among these groups suggest the proportion should probably exceed their proportion in the population. Steps need to be taken to ensure that Districts with lower participation rates are targeting outreach efforts at these communities.
- The Infant Toddler Program has had success increasing physician referrals by targeting them for outreach and education. However, the percentage tends to decrease once targeted efforts are cut back. There is a need to explore long-term strategies for informing physicians about the program. Doctors are responsible for about 18 percent of referrals into the Infant Toddler Program.
- The Infant Toddler Program is facing a major challenge meeting its new mandate to assess all children who are determined to have been abused or neglected. This mandate provides an opportunity for Infant Toddler to work closer with CFS. However, CFS workers are faced with high caseloads and other demands so the extent to which they will actually be able to be involved in this effort is uncertain.
- The partnership between the Infant Toddler Program and the Special Education Program to reduce the percentage of children exiting Infant Toddler without being assessed is a useful model for other partnerships across the State. Part of the success reflects the importance of performance measures in Federal reporting requirements for the programs. Both programs must report trends over time on a variety of measures and account for both progress and slippage. If there is slippage a description of what will be done to address slippage is required. A similar model can help focus the work of collaborative efforts in other areas.
- The State Special Education agency is working with school districts to ensure that assessment instruments are culturally and linguistically appropriate. There is a concern that some students for whom English is not their first language are being classified as Special Education students because of misuse of these tools and because alternative services are not available. As students are reclassified it is important that services are put in place which help them succeed in school and address other needs such as health education and health care access.
- The partnership between Medicaid and Special Education has been successful in allowing more schools to appropriately use Medicaid. This enables schools to provide needed services while freeing up resources for other programs and services. Despite concerns over rising Medicaid costs it is important that Medicaid continue to work with other agencies to encourage that Medicaid be billed for services when this is appropriate. In many cases these services are already being paid for out of State dollars and are needed to prevent higher costs later on. The Medicaid Program represents an opportunity to receive substantial reimbursement from the Federal government for services needed by the people of Idaho.

Idaho CSHCN Outcomes

- The Special Education Agency recognizes a need to improve transition services. This effort will need the participation of multiple agencies. Medicaid-funded care coordinators can play a role here if they are appropriately trained and have developed ties with other agencies and organizations. There is a need for training and certification procedures to ensure care coordinators are able to carry out their responsibilities for children with special needs.